

**SOCIETY'S  
STEPCHILDREN:  
THE  
MENTALLY  
RETARDED**

**RESEARCH REPORT No. 112  
(New Series)**



**COMMONWEALTH OF KENTUCKY  
LEGISLATIVE RESEARCH COMMISSION**

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# **SOCIETY'S STEPCHILDREN: THE MENTALLY RETARDED**

**Prepared by  
George Reuthebuck**

**Research Report No. 112**  
***Legislative Research Commission***  
***Frankfort, Kentucky***  
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## FOREWORD

This report, offered in response to Senate Concurrent Resolution 48 of the 1972 Regular Session of the General Assembly, examines and evaluates the State's programs relating to the care and treatment of those classified as mentally retarded.

The reader is also referred to the final report of the Health and Social Service Facilities Review Commission, a committee of legislators appointed by the Legislative Research Commission to make a related examination prior to the 1974 Regular Session.

JACKSON W. WHITE  
Director

The Capitol  
Frankfort, Kentucky  
April, 1974



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## I. INTRODUCTION

Senate Concurrent Resolution 48 of the 1972 Regular Session directed the Legislative Research Commission to make a comprehensive study and evaluation of the effectiveness of the mental retardation programs offered by the Department of Mental Health; the adequacy of such programs in relation to the total need of the mentally retarded, and the most effective situs for mental retardation programs in the organization of state government.

In order to accomplish these purposes, it seemed appropriate to determine:

- (a) adequacy - in terms of the extent to which Kentucky's population of mentally retarded have services available (a supply/demand issue); For additional information on adequacy the reader may wish to refer to Legislative Research Commission's Staff Memorandum #374, "State Aid to Parents of Retarded Children."
- (b) effectiveness - by accomplishing before and after comparisons of the capabilities of the mentally retarded; and
- (c) the most effective administrative location in state government - by examining the services needed by the mentally retarded in relation to the services rendered by various state agencies.

Rather than accepting the results of (a), (b), and (c) by themselves, it was determined to be more beneficial to examine (a), (b) and (c) in relation to past trends.

Heretofore...

In Kentucky, one may find a dismal history of treatment for the mentally retarded. The following excerpt from a 1951 Legislative Research Commission publication describes the state's provisions for caring for the mentally retarded:

"Kentucky recognizes her responsibility for the mentally deficient in two ways. One---through provision of institutional care for the feeble-minded at the Kentucky Training Home. The other---by 'subsistence' grants to pauper idiots."

The Kentucky Training Home (formerly the State Institution for the Feeble-Minded, currently the phased-out Frankfort State Hospital and School) was administered by the Department of Welfare. Although the name of the facility indicated 'training' was intended, conditions in the facility were such that custodial care was the primary application.

Hope for the retarded individual was minimal at the time. It was indicated that since there were no treatment programs and facilities were inadequate, the chance of a resident's release was slight. Of the few who were released, it was reported that 75 percent were "released" as escapees, parolees or deaths.

Overcrowding seemed perpetual in the 1950's. The capacity of the Kentucky Training Home was 616. As many as 1129 have been reported living at the facility. The prognosis for more space seemed futile, since the waiting list comprised as many as 650 persons; in addition, another 450 persons were reported to have been under care in facilities for the emotionally disturbed.

In most cases, the patient/staff ratios were well under the national averages.

Additionally, the average expenditure per patient for Kentucky was \$1.22 per day, while the national average was \$1.73 per day.

Recommendations were primarily devoted to expansion of the facility (to a capacity of 2,000) and increasing the quality and quantity of staff.

In tracing the progress of mental retardation programs through the 1950's, one finds evidence of overcrowding, understaffing, and few discharges. The 'treatment' of the mentally retarded was as archaic as was much of the terminology, (feeble-minded, idiots, morons, imbeciles). References made to those in institutions included inmates and patients.

Some of the programs and terminology have persevered. Primarily, the concept of special education and its terminology have survived the multitude of transitions with respect to vogue terms and programs.

Programs for the mentally retarded remained administratively housed within the Department of Welfare until 1962, although the Department of Mental Health was created in 1952.

Current trends in the field of mental retardation seem to indicate a thrust of community programs with a de-emphasis on institutional settings. Community treatment is becoming prevalent in corrections, in the treatment of 'mental illness', in public health generally, and in mental retardation.

Nirje's "Normalization Principle" serves as an underlying theoretical basis for the treatment of mental retardation (1970). In essence, the Normalization Principle indicated that mentally retarded individuals should be exposed to 'normal' influences. It seems plausible, then, to consider the Normalization Principle as a 'yardstick' with which programs for the mentally retarded may be measured.

Federal legislation for the field of mental retardation apparently awakened with the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 (P.L. 88-164). Among the various provisions of the Act was a requirement for a state plan with regard to mental retardation. For the purposes of this study, the provisions of the state plan which are of primary concern were the designation of a state advisory council and setting forth the relative need for projects.

In 1964, an executive order (64-206) was issued which created the Kentucky Mental Retardation Planning Commission. The Planning Commission was divided into ten task forces in the areas of prevention, research, clinical services, residential care, community services, special education, vocational rehabilitation, coordination, records and reporting, and public awareness.

After the task force examined their respective areas, each task force reported its findings and made recommendations in 1965.

### Procedures

Conceptually, effectiveness may be described as how well something is accomplished. Similarly, in the present study, effectiveness was construed as indicating how well various 'treatments' were applied to the mentally retarded. More specifically, one may interpret effectiveness, in the case of mental retardation, as being reflected by the extent to which one has lost those qualities which made him eligible for his title. If one did, in fact, lose those qualities then it should follow that he would lose his title: "mentally retarded." Unfortunately, the various problems associated with the mentally retarded are such that one is not likely to lose all of the characteristics which made him eligible for his label. It is more likely that some of the characteristics (or lack of characteristics) may be lost, thus enabling the retarded to more closely approximate a "normal" individual's characteristics.

Within such a framework of "effectiveness", one may find himself better able to discuss degrees of effectiveness, as opposed to: "effective" or "not effective."

The ultimate degree of effectiveness, then, may be when a client loses enough undesirable characteristics to a point where he is released from a residential facility. The converse also may be appropriate in that effectiveness may be measured in terms of attaining a number of desirable characteristics.

The practicality of obtaining these measures of effectiveness was not optimal because consistent information was not readily available on all retarded clients who were participating in programs administered by the Department of Mental Health. The Day Care program administered under Title I of the Elementary and Secondary Education Act was apparently the only program started to obtain measures for its clients, other than the residential facilities.

#### Diagnosis/Classification

The two primary professional fields associated with the diagnosis of mental retardation are the medical and behavioral science professions.

Various "ivory-tower" disagreements took place in the late 1950's and early 1960's (some of which may still exist) with regard to the diagnosis of mental retardation. Primarily, the disagreements were attributable to the classification systems for mental retardation.

Beaumeister (1967) reviewed various diagnostic techniques which reflected the prognosis for the mentally retarded. Some professionals believed that mental retardation was incurable, hence, whenever a "mentally retarded" individual showed some improvement the same professionals would say that the individual was misdiagnosed.

Currently, there are several diagnostic schemes which seem credible, yet practical, for those who deliver services to the mentally retarded. The diagnostic scheme of the American Association on Mental Deficiency seems to be more appropriate for the purposes of this document. Table I indicates that the two primary factors involved in determining mental retardation are intellectual functioning and adaptive behavior.

The AAMD defines mental retardation as:

"...significantly sub-average general intellectual functioning existing concurrently with deficits

in adaptive behavior and manifested during the developmental period."

It is significant to note that 'cause' is disregarded, and the current functions of the individual are stressed in the AAMD's definition. In the above definition, "intellectual functioning" is reflected by a score on a standardized intelligence (IQ) test; and adaptive behavior are taken into account when assessing mental retardation.

TABLE I: DIAGNOSTIC MATRIX FOR MENTAL RETARDATION

		<u>Intellectual Functioning</u>	
		Not Retarded	Retarded
<u>Adaptive Behavior</u>	Not Retarded		
	Retarded		X

Within the general classification of mental retardation there are diagnostic categories reflecting the degree of mental retardation. The diagnostic categories according to AAMD standards are mild, moderate, severe and profound (1973). The following table compares the AAMD terminology with the roughly equivalent terminology of the field of education:

<u>AAMD</u>	<u>Education</u>	<u>Measured IQ</u>
Mild	Educable	55-69
Moderate	Trainable	40-54
Severe	(dependent/custodial)	25-39
Profound		-24

With regard to adaptive behavior, standardized tests such as the Adaptive Behavior Scale, the Vineland Social Maturity Scale and the Fairview Self-Help Scale are available. The Vineland measures what an individual does in his daily activities, ultimately yielding a Social Age (SA) and Social Quotient (SQ) similar to some IQ tests (Anastasi, 1968). The Fairview measures similar factors, but in a more precise manner, ultimately eliciting a Behavioral Age (BA) and Behavioral Quotient (BQ).

On the other hand, there seems to be a trend to de-emphasize the use of psychometrics (psychological testing). The use of psychological tests in measuring "intelligence" has been professionally scrutinized for some time. Wechsler defined intelligence as ... one's global or innate ability to think rationally, to act purposefully and to deal effectively with one's environment. Conceivably one could construe the definition to stress the appropriateness of an individual's behavior relative to his environment and regardless of that environment.

There are those who believe that the mentally retarded should not be classified in categories because categorization represents a departure from normalization. Thus, a departure from normalization would inhibit attempts to assimilate a retarded individual into the mainstream of daily living.

As a result of the trend to decategorize, such classifications as "developmental disabilities" have been created. Although such terms still represent labels, the labels are more general and less confining for the individuals wearing them.

For example, a rural 6-year-old child, who knows the surrounding ten miles "like the back of his hand," can effectively manipulate his environment because he is knowledgeable about his rural culture. On an IQ test, however, this child may yield an IQ score indicating he is mentally retarded.

Another example may be a ghetto child who, at the age of 9, can "pick" any lock, "hot-wire" any car, and "con" most passers-by out of a dollar. He is dealing effectively with his immediate environment, but he might make an inferior score on an IQ test.

In both examples, the children have adapted to cultures which are not likely to correspond to a "middle-class" or a "typical" culture.

These two examples are analogous to giving a German IQ test to middle-class American children. The middle-class American children may score in the retarded range simply because they do not speak the test's language.

Although this discussion may smack of academia, a number of recent court cases indicate the practicality of examining the classification of mentally retarded through the use of psychological testing.

A district court in California entered a preliminary injunction to prohibit the state from using IQ tests with minority groups. Certain groups were being given intelligence tests, classified, and placed on the basis of test scores alone. A final decision had not been made by December, 1973.

When some decision is to be made regarding the appropriate treatment for an individual, an intelligence test can be an effective starting point. Suppose the middle-class American youth was administered the German IQ test. If the American youth made an inferior score one might be in a position to say that the child had not adapted to the German environment. True; however, one may not necessarily say the child is mentally retarded until the reasons for his scores have been investigated. Upon investigation, the qualified administrator of the IQ test would undoubtedly determine that the American child's handicap was simply an inability to speak the German language. Obviously it would not be appropriate to label the American child "mentally retarded."

A case was presented at the A.A.M.D. Convention in 1973 that was an opposite of the hypothetical example above. A Mexican-American child who did not speak English was having difficulty in his school performance. The child was referred to a counselor who administered an intelligence test. Since the child's score was in the mentally retarded range he was committed to an institution. Luckily, he escaped when he was older. The speaker at the A.A.M.D. conference indicated that the child had grown up and now was finishing law school.

While attending meetings, and conferences, conducting interviews and reviewing numerous documents, rumblings of a distaste for "labeling" became apparent. Much evidence exists to support the idea that labeling may become a self-fulfilling prophecy. For example, when one is known to be a juvenile delinquent or mentally retarded, one inevitably is treated as delinquent or retarded, and one may believe he is delinquent or retarded, thus behaving as a delinquent or retarded individual behaves.

Research indicates that teachers' expectancies are more affected by students whose labels indicate lower performance than by students whose labels indicate high performances. A recent paper by Spielberg (1973) indicated that teachers' reactions to children were a function of the children's labels, not their performances. The teachers' "knowledge" of a child's label, mentally retarded, inhibited the performances of children whose IQ's were actually 115 to 120.

In order to avoid such atrocities, the state of Texas (according to the PCMR Annual Report, 1972) has de-emphasized labeling and "special education" classrooms in order to move handicapped children into the mainstream. Labels and the expectancy of low performance are diminished considerably.

Another view point regarding classification is expressed by professional groups. Contrary to the belief that "labeling" should be abolished, some believe that classification systems are necessary for communication between professionals.

## II. LEGAL ISSUES - RIGHTS

Recently, a number of milestones have been observed with regard to law and the mentally retarded. Two primary issues in the flourishing court activity are the right to an education and the right to treatment. A third right to a fair classification, is covered in the Diagnosis/Classification section of this report. Court cases in the field of mental retardation have appeared in Florida, Minnesota, Connecticut, New York, North Carolina, Wisconsin, Maryland, Massachusetts, Iowa, Illinois, Georgia, Alabama, Washington, D.C.; Tennessee, California, Louisiana, Pennsylvania, Indiana, and Michigan as of February, 1973.

In 1971, a suit was filed against the State of Pennsylvania challenging the state's failure to provide an education to all retarded children. Education was defined as "a continuous process by which individuals learn to cope and function within their environment." Since the definition of education was not restricted to traditional academic endeavors, the suit had far-reaching implications for treatment or training of the mentally retarded.

The court's decrees, finalized on May 3, 1973, were: (a) "Due process" in the form of a formal hearing must be given whenever a child's educational status is being considered for change, and (b) the state could

not deny mentally retarded children access to an education supported by public funds.

In Washington, D.C., a class action, Mills v. D.C. Board of Education, was brought against the District of Columbia for reasons similar to those in the Pennsylvania case. Some of the children represented in the class action resided in residential facilities which had no provisions for education.

The court ordered that all children of school age must be identified, described and educational provisions made for all of them.

The first court case regarding the right to treatment was Wyatt v. Stickney in Alabama. The case charged that the state was involuntarily committing patients to hospitals for the mentally ill and not providing adequate treatment. Partlow State School and Hospital (for mentally retarded clients) was included as a defendant since allegations implied inadequacies in the habilitation of the mentally retarded. Partlow was described as being detrimental to any habilitative endeavors.

The district court issued an emergency order directing the state to hire 300 aids in a period of 30 days. The final order on April 13, 1972, established standards for care and a plan for implementation.

Primarily, the issue of a "right to treatment" has raised questions in terms of its constitutionality and its morality. When an individual is committed to a rehabilitative facility and receives custodial care, he has been deprived of the treatment that was intended. "Failure of state to provide suitable and adequate treatment to the mentally ill involuntarily hospitalized at state mental health hospitals could not be justified by lack of staff or facilities, and to deprive any citizen of his or her liberty upon altruistic theory that confinement is for humane therapeutic reasons and then fail to provide adequate treatment violate the very fundamentals of due process." 325 F. Supp. 781 (1971).

On the other hand, the decision in the Burnham v. Georgia case did not interpret the Constitution in the same manner as the Alabama District Court. Judge Smith (N.D. Georgia) concluded that the Georgia Constitution does not explicitly guarantee a right to treatment because the obligations to provide treatment was of a moral instead of a legal nature. Judge Smith additionally interpreted the Eleventh Amendment as prohibiting a federal court from requiring the expenditure of state funds for activities legally controlled by the state.

In order to prevent future instances of violations of the rights of the mentally retarded, a "Bill of Rights" for the retarded has been under various degrees of consideration. There appear to be two ways to interpret the implications of a bill of rights for the retarded:

- (1) Obviously, a separate Bill of Rights may be necessary to assure drawing attention to the fact that the mentally retarded have rights.
- (2) If there is going to be a Bill of Rights for the retarded, there should be a Bill of Rights for Blacks, Mexican-Americans, juvenile offenders, adult offenders, the mentally ill, older persons and any other group whose rights have been neglected.

The rights of the mentally retarded already are secured along with the rights of everyone else.

In 1954 the World Health Organization's Joint Expert Committee on the Mentally Subnormal Child, wrote:

"Every child has the right to develop his potentialities to the maximum. This implies that all children, irrespective of whether or not they suffer from mental or physical handicap, should have ready access to the best medical diagnosis and treatment, allied therapeutic services, nursing and social service, education vocation preparation, and employment." (emphasis added)

To take the concept a step further, why should opportunities and rights of any person be denied? Assurance of rights appears to be an enforcement problem rather than a problem of listing or declaration.

### III. ADMINISTRATION IN KENTUCKY

For the purposes of this document, programs administered for the mentally retarded will be discussed in two categories: community programs, and institutional programs.

Prior to the Governor's Reorganization Executive Order No. 6 of August 29, 1973, the Department of Mental Health was statutorily responsible for providing programs to the mentally retarded. Figure I

represents the structure of the Department of Mental Health. The Governor's Advisory Council on Mental Retardation advised the Commissioner of the status of Mental Retardation programs. The two main divisions of the Department of Mental Health were the Bureau of Administration and Fiscal Management, and the Bureau of District Operations. Figure 2 is an expansion of the Bureau of District Operations. Under it was the Institute for Developmental Disabilities (IDD), which was responsible for mental retardation programs. The IDD was further divided into subdivisions which carried the responsibilities associated with implementing programs for the mentally retarded in communities and "institutions."

Since the Department of Mental Health was reorganized into the Department of Human Resources, the location of programs for the mentally retarded has changed. Figure 3 represents the tentative location of programs for the mentally retarded in the administrative structure of the Department for Human Resources.

Regardless of the type of program in which an individual ultimately participates, the basic "system" is illustrated in Figure 4. The "system" seems to be composed of ten steps, which reflect the degree of a client's participation in the system.

The initial steps are taken in the community by referral sources having some contact with a client. Table 2 indicates the number and 'status' of mentally retarded individuals referred to Comprehensive Care Centers by community sources during Fiscal Year 1971 72. As may be seen in Table 2, the most active referral source was "school" which accounted for 18.6% of total referrals.

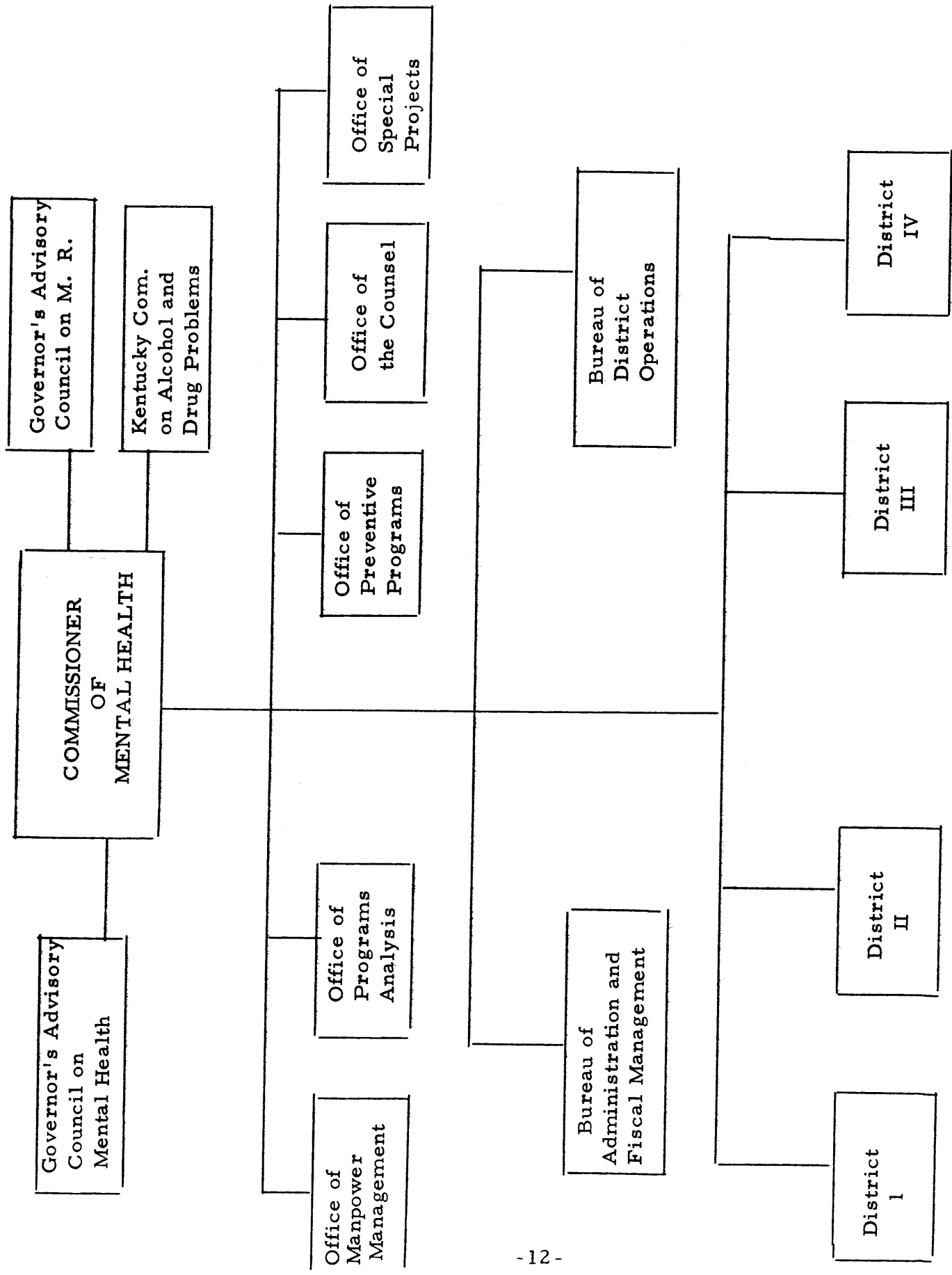


Figure 1. Administrative Structure of the former Department of Mental Health  
Source: Department of Mental Health

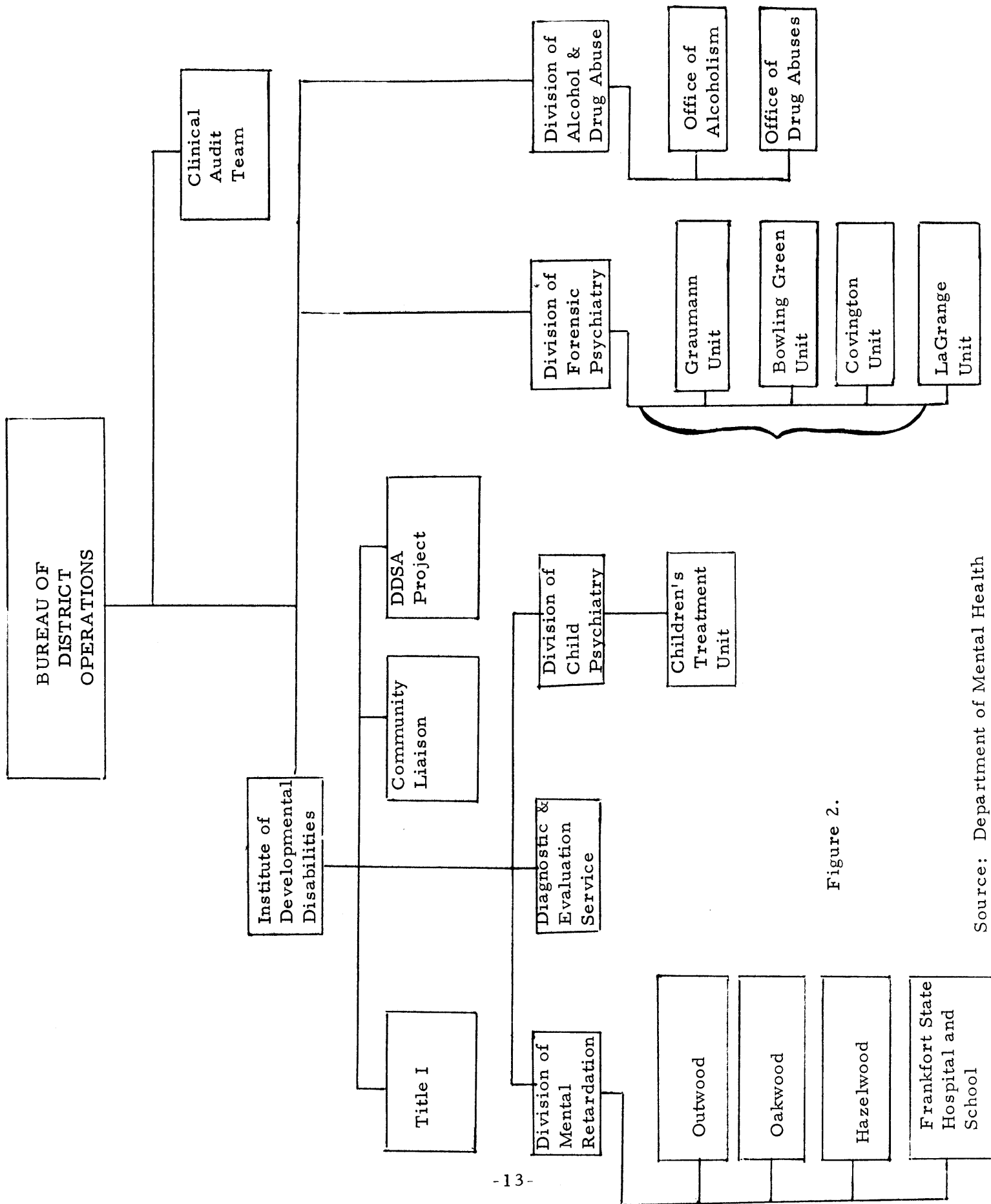


Figure 2.

Source: Department of Mental Health

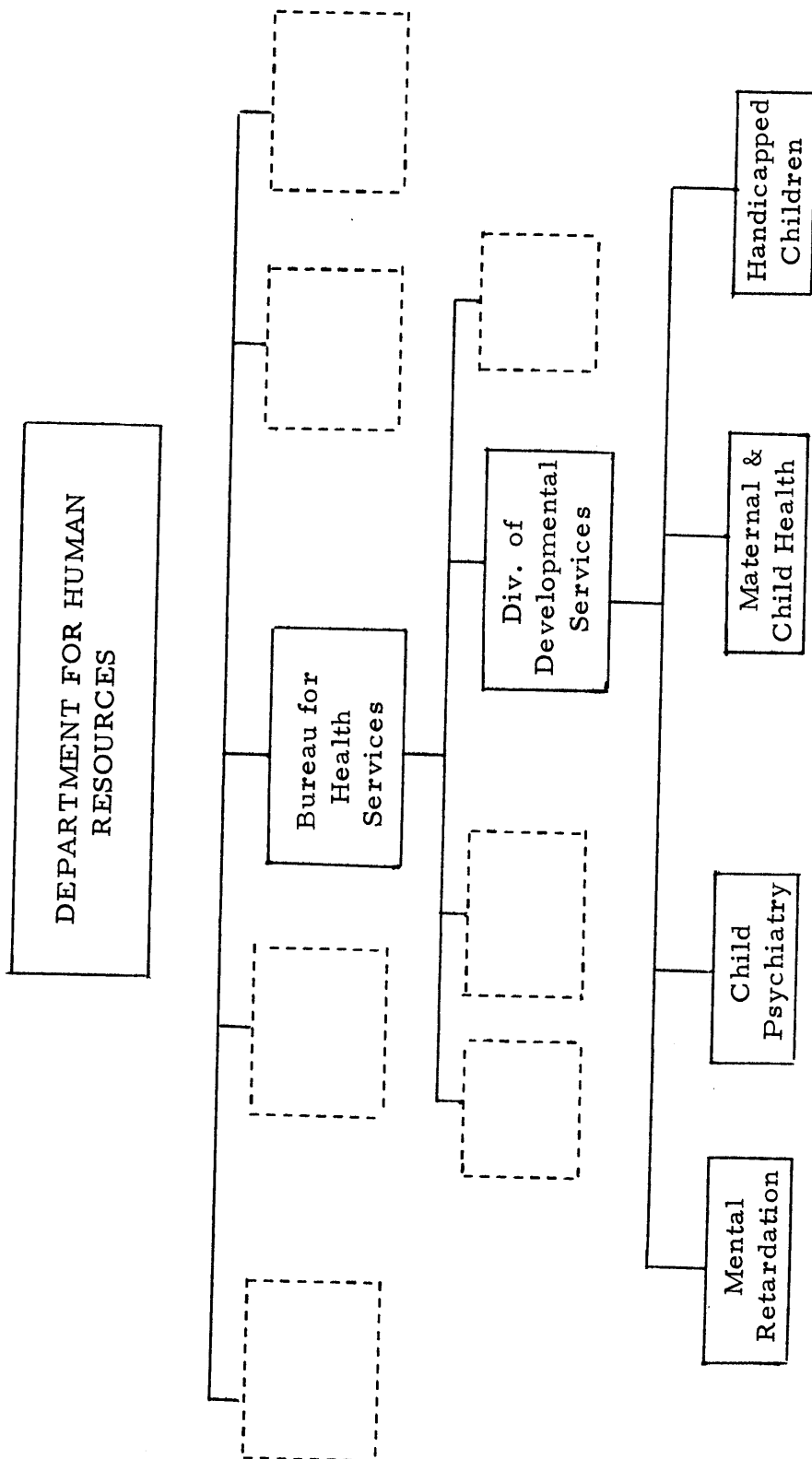


Figure 3. Tentative design for the location of mental retardation programs in the administrative structure of the Department for Human Resources.

Source: Department of Mental Health

DEPARTMENT OF MENTAL HEALTH  
INSTITUTE FOR DEVELOPMENTAL DISABILITIES

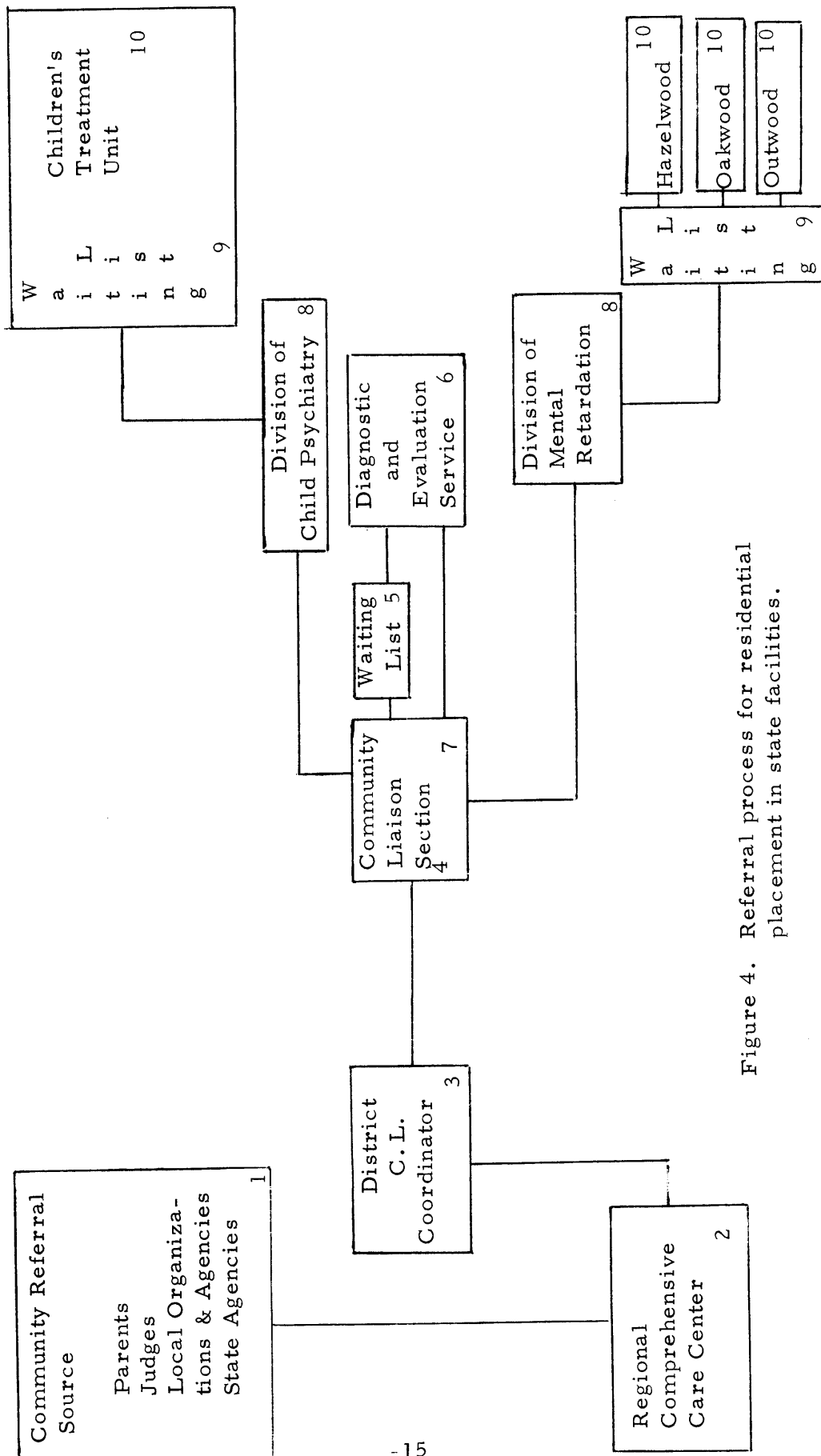


Figure 4. Referral process for residential placement in state facilities.

Note: Flow Chart; not indicating authority or hierarchy

Source: Department of Mental Health

TABLE 2

PERSONS SERVED - MR RELATED CASES, COMPREHENSIVE CARE CENTERS  
REFERRAL SOURCE BY PATIENT STATUS

FISCAL 71 - 72

REFERRAL SOURCE	PATIENT STATUS - ACTIVE				INACTIVE		Percent of Totals
	Inpatient	Outpatient	Day Care	Contacts	Terminated	Total	
Self	4	61	21	21	18	125	2.3
Family	7	192	185	93	100	577	10.7
Friend	2	46	69	18	24	159	2.9
Clergy	-	5	10	2	8	25	0.5
Private Psychiatrist	1	4	-	-	3	8	0.1
Other Private Physician	3	154	45	41	83	326	6.0
Comprehensive Care Center	3	63	88	26	13	193	3.6
Other Psychiatric Clinic	4	25	14	3	13	59	1.1
KDMH Hospital	30	484	51	23	80	668	12.4
Other Psychiatric Hospital (Inpatient)	5	32	1	8	7	53	1.0
KDMH Outpatient Clinic	2	92	7	2	14	117	2.2
Other General Hospital	-	35	10	4	11	60	1.1
Veterans Administration Hospital	-	2	-	-	1	3	0.1
School	3	185	266	182	367	1,003	18.6
Court	7	53	6	16	31	113	2.1
Voluntary Agency	-	26	36	7	19	88	1.6
Alcoholics Anonymous	-	3	-	-	-	3	0.1
Department of Public Health	-	72	70	29	42	213	4.0
Department of Public Welfare, Economic Security, Public Assistance	4	193	94	103	116	510	9.5
Department of Child Welfare	-	53	47	39	51	190	3.5
Department of Education	1	42	65	31	68	207	3.8
Other	4	84	98	44	68	298	5.5
Unknown (Not reported to OPI)	6	161	108	54	65	394	7.3
TOTAL	86	2,067	1,291	746	1,202	5,392	100.0

Source: OPI Computer Tabulation (DMH)  
Prepared by: Statistical Section.

Note: Number of MR related cases is an unduplicated count of persons.

## Community Programs

The community-based programs were not necessarily directly linked to the DMH, but may have been administered by local organizations in conjunction with a local Comprehensive Care Center. Generally, community programs for the mentally retarded were administered on a regional basis through the Regional Mental Health-Mental Retardation Boards. The fifteen Regional Mental Health-Mental Retardation Boards were the governing bodies of the 22 Comprehensive Care Centers(CCC's).

The statutory authority for Regional Mental Health-Mental Retardation Boards, and the programs which are established, is in KRS 210.370 through KRS 210.460.

The Department of Mental Health's relationship to the regional boards was clarified in KRS 210.450, which charges the Commissioner with responsibility to prescribe operating standards, rules and regulations for the boards, review and evaluate local programs, provide consultative staff for planning local programs, and employ qualified personnel to implement the programs.

The basic services offered by the CCC's were inpatient (IP); outpatient (OP); partial hospitalization (PH); consultation and education (C&E); information, screening and referral (ISR); and rehabilitation in the areas of mental health, mental retardation, alcoholism and drug abuse. Since mental retardation represented only a portion of the problems confronted by CCC's, a determination of the priority for mental retardation programs seemed to be in order.

Although the number of problems confronted by the regional boards were many, the priority for mental retardation programs appeared to be relatively high.

The Department of Mental Health had required the regional boards to have one-third of its members expressing a primary interest in mental retardation. It may be reasoned that if one-third of a membership was devoted to mental retardation, one-third of a board's activities, programs and funds very likely would have been devoted to mental retardation. Since each regional board must submit an annual plan and budget (AP&B) to the Department of Mental Health in order to qualify for state funds, these were reviewed in an effort to determine priorities given mental retardation programs. Although all A. P. & B.'s were not available at the time, it was felt that the available ones were sufficient to determine the priorities for mental retardation programs.

In essence, the overall priority for mental retardation programs did not appear to correspond with the priority for mental retardation on regional boards. Neither the funds nor the number of clients served represented one-third of the regional boards' activities. The total number of mentally retarded clients served by all Comprehensive Care Centers in fiscal year 1971-72 represented 17.2% of the total number of clients served. The following fiscal year (1972-73) 23.5% of the regional boards' estimated income was interpreted as being related to the field of mental retardation. With respect to service units and affiliates, 21.5% were interpreted to be directly related to mental retardation, 27.9% were interpreted to be partially or indirectly related to mental retardation, and 37.56% were apparently unrelated.

The largest category of services contracts with the local centers seems to be the local school systems.

### "Institutional" Settings

The Department of Mental Health was totally responsible for the administration of four mental retardation facilities: The Diagnostic and Evaluation Center (D&E) in Frankfort, Hazelwood in Louisville, Oakwood in Somerset and Outwood in Dawson Springs.

The general functions of each were as follows:

- |           |                                                                                 |
|-----------|---------------------------------------------------------------------------------|
| D & E     | - diagnostic functions for mentally retarded and emotionally disturbed children |
| Hazelwood | - extended care for nonambulatory mentally retarded individuals.                |
| Oakwood   | - extended care, medical/surgical and general mental retardation training.      |
| Outwood   | - extended care, medical/surgical and general mental retardation training.      |

### Diagnostic and Evaluation Center

The D & E Center was the intermediate step for mentally retarded individuals going from the community to a residential facility. It was somewhat unique relative to the other three facilities. It was small (bed capacity is currently being increased to 48), with a relatively high ratio of staff to clients, and the program was designed for short term visits up to a maximum of 30 days. Those received were either emotionally disturbed or mentally retarded.

Four sleeping wards replaced an earlier arrangement of one ward for boys and one for girls. They were for emotionally disturbed

boys, for emotionally disturbed girls, for mentally retarded boys, and for mentally retarded girls.

The services rendered by the D & E Center included crisis intervention, diagnostic services and a contingency management system. With regard to crisis intervention, D & E seemed to provide emergency shelter incases where it was necessary to remove a child from his community. That is, if D & E is notified of an emergency whereby a child, his family or the community are physically or psychologically endangered, the child is taken to D & E.

The diagnostic functions of the D & E Center were primarily concerned with psychometric indices of intelligence, adaptive behavior and brain damage. The Wechsler scales were used to determine "intelligence" in addition to the Goodenough and Cattell. The Bender-Gestalt was used to determine brain damage (D & E was also using the Bender for memory testing). The Fairview Self Help Scale and Vineland Social Maturity Scale were used to determine adaptive behavior.

Contingency management, an application of learning theory research, was utilized at the D & E Center in order to shape appropriate behaviors. A child may be taken to an isolated area where his behavior is studied more intensively. If a staff member wanted a child to quit yelling, for example, whenever the child paused, a piece of candy was placed in the child's mouth in order to reinforce "not yelling." This procedure could continue until quiet periods became more frequent and more intense, at which point the child must have remained quiet longer for each reward. Upon extinction of the yelling behavior, more appropriate behavior, such as giving attention to an object placed before him by the staff member, would be rewarded.

### Oakwood

Oakwood is a relatively new \$13.4 million facility located in Somerset. The facility projects a community-like atmosphere within its cottage living arrangement. Unlike the sterile institutions of days past when the mentally retarded were warehoused in dismal wards, Oakwood is a facility which approximates a "normal" environment.

The capacity of Oakwood was 444. At the time Oakwood was visited, there were 390 residents and a total of 580 staff members.

The administrative structure of Oakwood may be observed in Figure 5. Since this document is primarily concerned with programs, the Program Branch will dominate the following discussion in addition to Oakwood's general management.

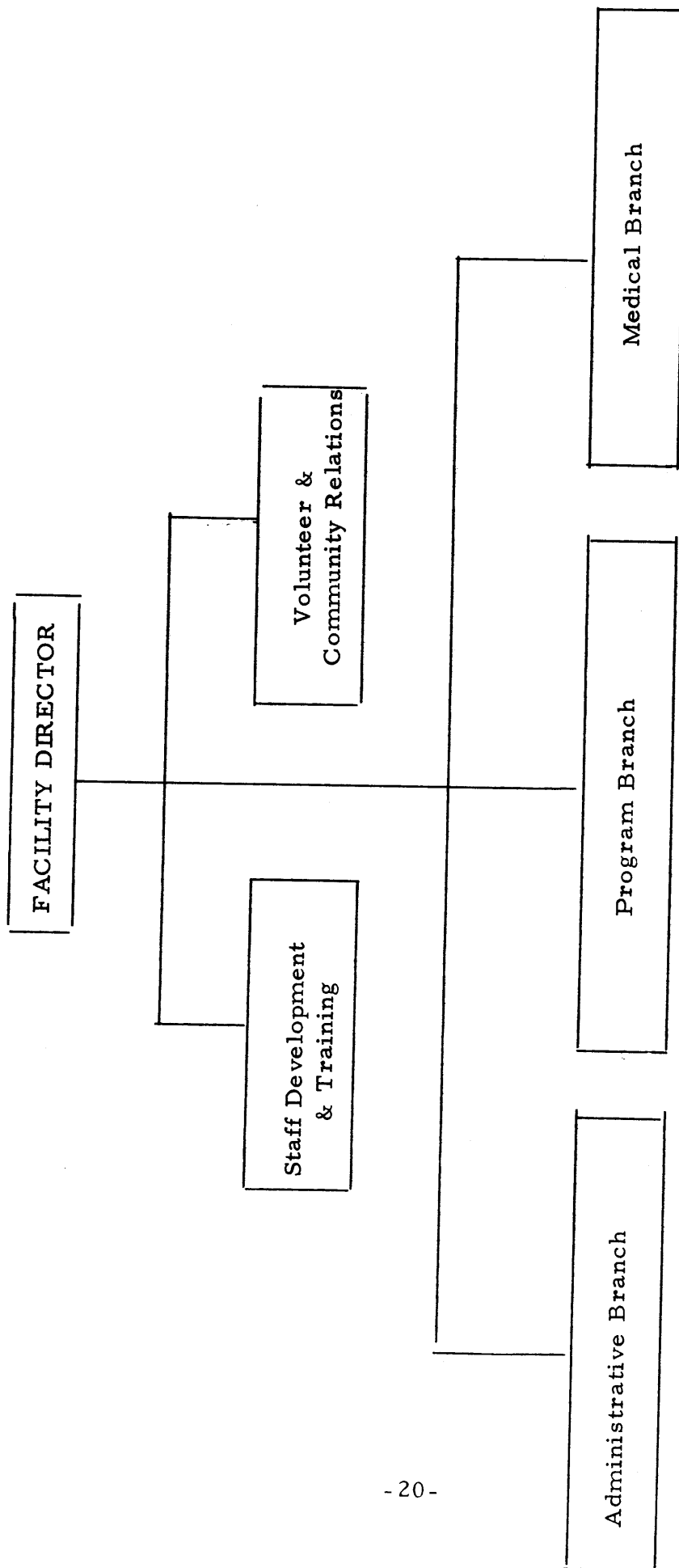


Figure 5. Administrative Structure of Oakwood

Source: Oakwood (July 1973)

Programs at Oakwood seem to be continual, planned and individualized. Such programming seems to be in contrast with reports of custodial treatment in the past when programs seem to have been infrequent random events in an environment of hopeless apathy.

Since Oakwood has been in its infancy it has experienced a number of growing pains. A portion of these growing pains were manifested in a 60% staff turnover during the first year. Another growing pain was apparently felt when a Pulaski County grand jury investigated Oakwood in regard to a number of allegations (which were later dismissed).

The general management of Oakwood was such that the staff was building its objectives and determining means of reaching them in dealing with residents, as well as other staff personnel.

A Management by Objectives (MBO) approach has been initiated for staff. Although it had not been in operation for a period of time which was conducive to evaluation, it seemed to represent a reasonable means of forming an operating framework for staff. The MBO system simply required staff to determine what objectives were to be reached, how the objectives were to be met, and when the objectives were to be met. The resultant feedback (going to the individual who had set "what, how, and when" the objectives were to be met) ultimately seemed to serve to keep realistic activities in the foreground.

Programs were administratively housed in the Program Branch, which was under the supervision of a Program Director, under whom were the Unit Directors and Supportive Services. The Unit Directors were responsible for every component of operation in the five Living and Training Units.

The Units were composed of a variable number of cottages with two apartments per cottage. The apartments were completely carpeted six-bedroom units (two residents slept in each bedroom), with a dining area (usually located at one end of the living room), a medications room (for each cottage), a classroom, a variable number of offices for staff, and a kitchen.

The programs for the residents basically consisted of applications of learning theories. Very simply stated, appropriate behavior was rewarded and inappropriate behavior was not rewarded. The means of applying the reward systems were varied not only in the types of rewards administered, but in the different contingencies for earning rewards as well.

Programs consisted of establishing goals to be reached by the residents. The goals could have been elementary, such as getting out of bed, making the bed, and getting dressed; however, the goals in the individual programs served to structure the residents' daily living to approximate a normal pattern of daily living.

Whenever residents achieved a goal, rewards were administered, either by tokens or points to be traded at a later time. For lower functioning residents a wide variety of primary rewards were used depending on what each resident found to be rewarding. The types of reinforcements were candy, coffee, a tongue depressor, a piece of string, milk, and one case, a green bubblegum cigar. Where cases were reported to have been in Frankfort State Hospital and School from 4 to 20 years with no programs or skills developed, such as toilet training, some have acquired basic skills such as eating in a "family style".

A relatively strong component in the programming of residents was Supportive Services. Supportive Services consisted of educational diagnostics and evaluation, pre-vocational training, recreation, religious nurture, barbering and beauty services, expressive therapy (art therapy, music therapy, and occupational therapy) and special classes for visually impaired, the hearing impaired, visual-motor/perceptual-motor impairments, and a service to teach home living (termed "practical Arts/Community Classroom").

Unfortunately, the staff shortage at Oakwood apparently was most detrimental to the Supportive Services division. Supportive Services were rendered inoperative because its staff had to assist in cottages.

### Hazelwood

Hazelwood was closed as a tuberculosis facility and transferred to the Department of Mental Health. The Department renovated the facility with air conditioning, paint, wiring and other remodeling procedures at a cost of almost \$1.5 million.

Hazelwood was reported to have a rated bed capacity of 202 while its occupancy was 227. It did not give the appearance of being crowded since some day rooms were reportedly being used for bed areas.

The individuals served by Hazelwood were non-ambulatory mentally retarded children and adults. That is, not only were the

individuals mentally retarded, but their primary disability was compounded by physical incapacities as well.

Hazelwood was a replacement for the "crib units" at the former Frankfort State Hospital and School, and Outwood in Dawson Springs. The phrase "crib unit" refers to the appearance of the beds in the ward areas which were chrome with high-barred sides to prevent falling. The number of beds per room ranged from two to four.

Classrooms composed one floor of one wing. The classes seemed relatively small with facilities in each for developing sensory and motor functions. Although the facility was unable to recruit a physical therapist, some degrees of physical therapy were being applied.

Staff salaries were reportedly uncompetitive not only for physical therapists, but for teachers as well.

With respect to food services, the dining area was apparently used by staff while meals were delivered to the wards in a manner similar to that followed by acute hospitals.

One building on the grounds was primarily being used for storage. The building had four potentially usable floors, only one of which was being used by the River Region Mental Health-Mental Retardation Board, which was not directly associated with Hazelwood.

### Outwood

Outwood was a tuberculosis facility owned and operated by the Veterans Administration until 1962. Built around 1920, Outwood was designed to last approximately thirty years.

At the time of the review Outwood's population was 326 with a bed capacity of 300 (three halls had been closed due to their dilapidated conditions) with 330 staff to work with the residents at Outwood.

Difficulty with an ability to recruit and maintain personnel was attributed to the geographical location and inadequate salaries. The only apparent drawing factor was an availability of staff housing on the grounds. Although there was not enough housing for all staff it seemed sufficient for a number of key personnel.

Outwood's food service facilities seemed spacious for the number of individuals who utilized it. The dining area was divided into a large room for the residents and a smaller semi-enclosed portion for staff. The halls where daily living and training took place were composed of sleeping areas ranging from semi-private rooms to approximately sixteen-bed wards. Most of the doorways to the sleeping units were unlocked so as to permit the individual to make his own decision to refrain from sleeping in the daytime.

"Time-out" rooms for seclusion were used for extremely disruptive behavior such as assaulting other residents or staff. Time-out rooms were found on most halls and in the school. Residents placed in these large closet-like quarters were to be checked frequently. All instances of placing residents into time-out rooms were to be logged.

The overall program at Outwood was an application of learning theory (Primarily in the form of a Skinnerian model) similar to Oakwood. Learning theory applied to the condition of mental retardation at Outwood was simply observing appropriate behavior and withdrawing rewards when inappropriate behavior occurred. The types of rewards used were similar to those at Oakwood: candy, tokens and points.

Special programs were found in the school which served to train residents in basic self-help skills such as bathing, perceptual-motor tasks, like coordinating hand movements with objects seen; increasing vocabularies, academic skills and home living skills. No speech and hearing therapy was available at the time of the review.

For additional information on mental retardation facilities, the reader may wish to examine the Health and Social Service Facilities Review Commission Final Report.

#### IV. FINDINGS

Since the 'adequacy' of programs for Kentucky's mentally retarded has been prefaced by a discussion of supply and demand, a continuation of 'supply-demand' findings may be in order.

A general "rule of thumb" for projecting the population of mentally retarded is 3% of the total population (or 96,561 mentally retarded in Kentucky). However, some have indicated that 3% of the birth population may be mentally retarded, most of whom, by some means, lose their characteristics by adolescence. Consequently, at any point in time, only one percent of the total population is thought to be mentally retarded.

Another complication to estimating the number of retarded individuals develops when one considers Kentucky's uniqueness. According to the President's Committee on Mental Retardation (1972), 17% of the Appalachian population is mentally retarded. Kentucky has 49 "Appalachian counties," the total retarded population of which may be estimated to be 149,005.

A study by Tarjan, Wright, Eyman and Keenan (1973) reinforces the idea of a high prevalence of mental retardation in unique areas. This study estimated the prevalence of mental retardation in a prototype community and specifically excluded ghetto and rural areas, the reason given being that individuals from those areas are 15 times more likely to be labeled "mentally retarded" than their suburban counterparts.

On the basis of all factors, one can project a wide variety of estimates of Kentucky's mentally retarded population. The lowest estimate would be 1% of Kentucky's total population (3,218,706), or 32,187 mentally retarded individuals in Kentucky. The highest estimate may be based on 3% of the population weighted by 17% of the Appalachian population for a total of 219,271 mentally retarded individuals.

Regardless of which estimate one accepts, it is extremely difficult to determine the numbers and types of services that are needed for the various degrees of mental retardation. How many of those need institutionalization, day care, sheltered workshops, half-way houses or special education in public schools?

Although it seems to be accepted that 89% are mildly retarded, 6% moderate and 5% severely and profoundly retarded, it would be a monumental task to determine the intensity of treatment and the type

of service needed for every person in the mental retardation categories. According to Roos (1973) one may expect the mildly retarded to be capable of gainful employment and independence, and the moderately retarded to contribute to society through sheltered employment.

A mildly retarded 18 year old may need institutional care as much as a profoundly retarded 14 year old. This is not to say that both may be expected to receive residential treatment for the same lengths of time; to the contrary, another factor compounding the 'demand' for services is the length of time for treatment services in addition to the numbers and types of treatment services.

This review of programs for mentally retarded individuals encompassed more than the Department of Mental Health. Although SCR 48 was concerned only with programs offered by the DMH, it was determined necessary to include the number of mentally retarded served by the Department of Education. According to the Division of Special Education's "Status Report," the number of mentally retarded individuals served by special programs was 14,340. (The report indicated that 17,911 retarded children need special programs in public schools.)

The number of retarded children in special education programs apparently did not include a portion of the school age population who were severely and profoundly retarded.

Another component of the Department of Education's role in serving the mentally retarded is the Community Workshop service provided through the Bureau of Rehabilitation Services. The Community Workshops were reported to have served 1,931 individuals during fiscal year 1972-73. A rough estimate of the proportion of that total who were mentally retarded was 50% or 966 mentally retarded individuals served by community workshops.

The Department of Mental Health was responsible for providing services to the mentally retarded through residential facilities and community programs (including Developmental Training Centers, Adult Activity Centers and Group Homes). The number who had been or were projected to be served was 2,961 (in November 1972).

The number of individuals who could be served by the residential facilities was estimated to be 967, based on the total capacity of all three residential facilities.

In addition to those who participated in some type of program designed for the mentally retarded, 395 retarded individuals were

reportedly housed in the district mental health facilities (as of June 30, 1972).

Another 279 mentally retarded individuals were reported to have been receiving custodial care in personal care homes (Governor's Advisory Council on Mental Retardation, 1972; Council for Retarded Children of Jefferson County, 1972).

In summarizing the 'adequacy' of programs for the mentally retarded, one may reasonably presume that the number of available programs are grossly inadequate. A total of 19,118 mentally retarded individuals may be estimated as being a current or projected participant in some type of program. This figure includes the capacities of the residential facilities, the approximate number served in special education programs, those individuals in mental health facilities, personal care homes and 180 in a private facility for the mentally retarded. The exact number served by other private sources is unknown.

Whether one accepts the estimate of 32,187 or 219,271 mentally retarded individuals in Kentucky, the estimated remainder ranges from 13,069 to 200,153 retarded individuals not receiving services administered directly or indirectly by state agencies.

Time did not permit an examination of the appropriateness of the placement of 395 mentally retarded individuals in mental health facilities. However, the mental health facilities apparently had no special programs for the mentally retarded.

With respect to personal care homes, evidence indicated that placement of mentally retarded in personal care homes is inappropriate.

### Effectiveness

Effectiveness data was obtained for Outwood, Oakwood and a private facility which had received a number of placements from state facilities. Equivalent data on Hazelwood was not obtained. In the cases where data was obtained, staff had taken measures on the adaptive behavior of the residents.

Data provided for Outwood had been compiled and statistically analyzed by Outwood's staff; both compilation and analyses were shared with the author for this report. Mr. Richard King, Bureau for Health Services, supplied the author with data on Oakwood and the private facility. Mr. King's

data was gathered partially for the purpose of his doctoral dissertation.

Outwood used the Adaptive Behavior Scale (ABS), developed by the American Association on Mental Deficiency, to measure the effectiveness of their programs. The ABS has sections designed to detect adaptive behavior and maladaptive behavior. The Adaptive Section has ten subscales: independent functioning, physical development, economic activity, language development, number and time concept, occupation-domestic, occupation-general, self-direction, responsibility and socialization. The Maladaptive Section has fourteen subscales: violent and destructive behavior, antisocial behavior, rebellious behavior, untrustworthy behavior, withdrawal, stereotyped behavior and odd mannerisms, inappropriate interpersonal manners, unacceptable vocal habits, unacceptable eccentric habits, self-abusive behavior, hyperactive tendencies, sexually aberrant behavior, psychological disturbances, and use of medication.

For the purposes of this document total scores for each of the two major scales (Adaptive and Maladaptive) will be presented rather than the subscale scores. Figure 6 represents a pre-post comparison of average scores in adaptive and maladaptive behavior for residents in one hall at Outwood. The time lapse between testing periods was six months.

As may be seen in Figure 6, an increase in adaptive skills occurred while a concomitant decrease in maladaptive behavior may be observed. The increase in adaptive skills was determined to be statistically significant; however, the decrease in maladaptive behavior was not significant.

The 'effectiveness' data for Oakwood and the private facility was measured by Behavioral Age changes effected by the Fairview Self-Help Scale. The first administration of the Fairview took place at Frankfort State Hospital and School prior to the residents' transfer to Oakwood and the private facility. The second test administration took place six months later at the residents' new facility.

Figure 7 represents the average Fairview scored for the residents at Oakwood and the private facility over the two testing periods. It is apparent that residents in both facilities increased their self-help skills. Since the data was confounded by a number of variables statistical analysis was not accomplished. That is, it would be difficult to attribute the relative changes to Oakwood and the private facility since different individuals tested the residents

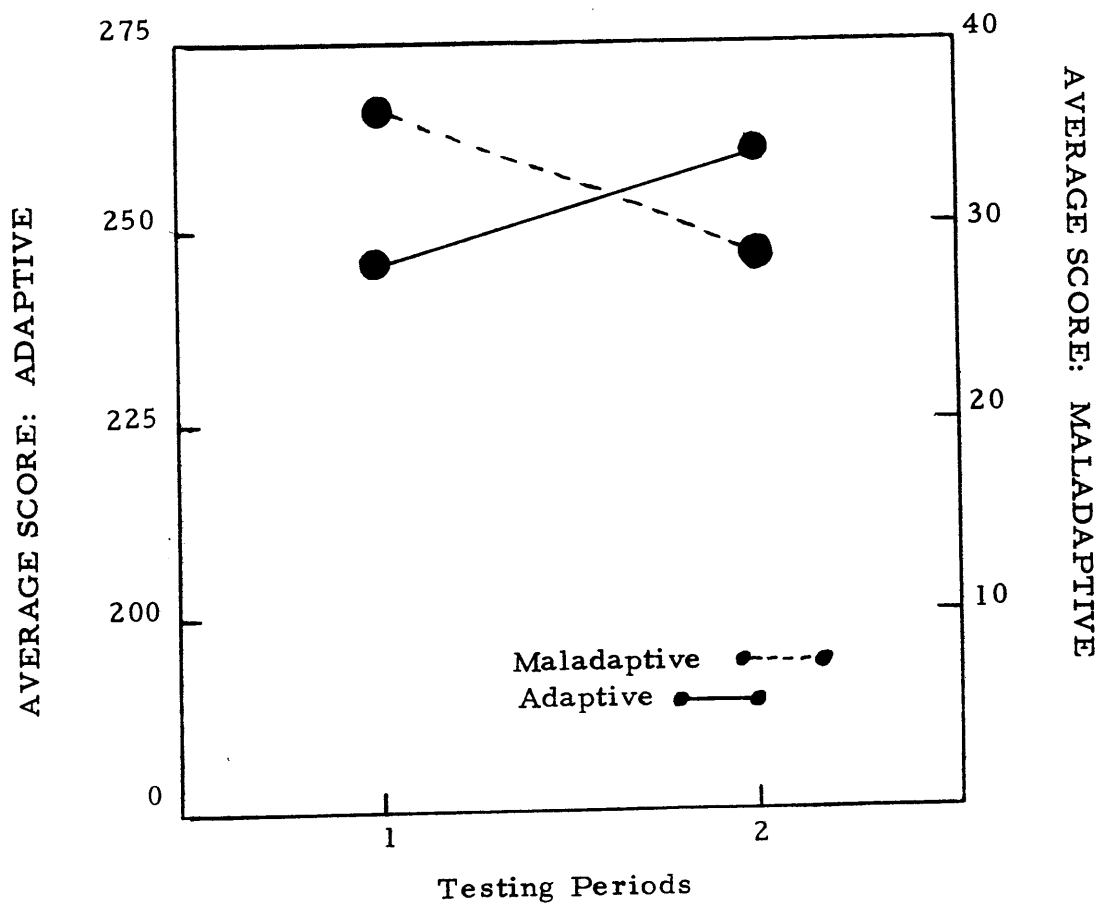


Figure 6. Average adaptive and maladaptive scores for testing periods 1 and 2 at Outwood.

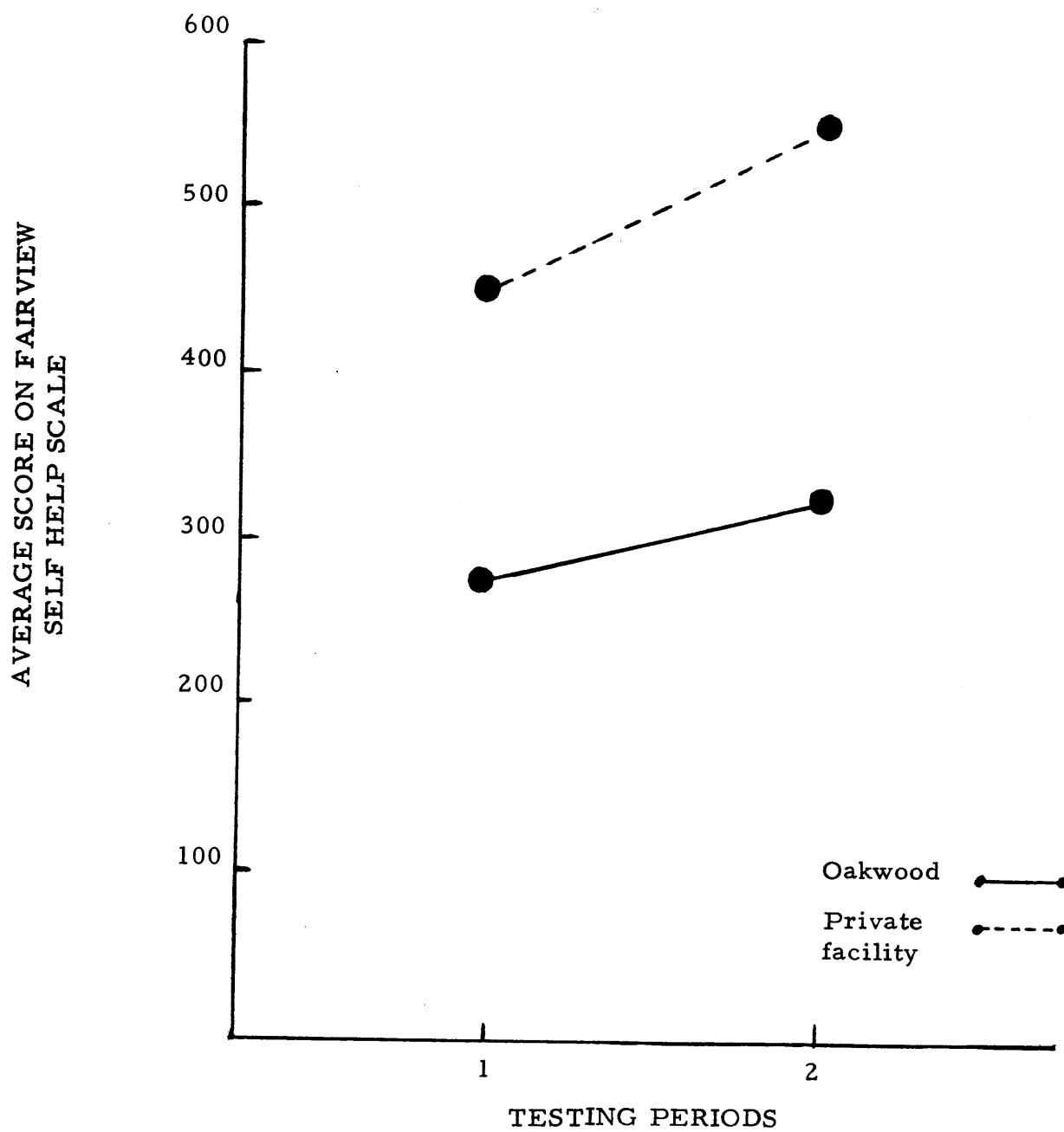


Figure 7. Average Fairview self help scale scores for residents at Oakwood and a private facility over two testing periods.

in the "before" and "after" phases. The increases in self-help skills could simply be a random fluctuation of the different raters' perceptions of the skills that were evaluated.

A comparison between Oakwood and the private facility was not feasible since the two groups of residents differed in age, sex, diagnosis, behavioral level and length of institutionalization. Although it is apparent from Figure 7 that the rate of increase was greater for the private facility than Oakwood, one may not be in a position to say that the private facility is "better" than Oakwood on the basis of the data presented. The relative changes for the two facilities were similar inasmuch as the average increase for Oakwood was 17% and 21% for the private facility.

Overall effectiveness of programs for the mentally retarded may also be measured by other factors. Since the ultimate degree of effectiveness seems to be placement out of a facility into a community setting, it may be appropriate to examine the releases that have occurred from state residential facilities for the mentally retarded.

In fiscal year 1971-72 the average length of stay for cases separated, including discharges and deaths, from residential facilities was 3,728 days. The average length of stay for cases separated between June 1972 and April 1973 was 2,737 days. Of the 285 cases terminated by CCC's in fiscal year 1971-72, the average length of stay was 467 days.

#### Most Effective Site in State Government

The types of services needed by the field of mental retardation appear to cover a number of dimensions. Among those dimensions are health needs, habilitative needs, educational needs and social service needs. It is apparent that an umbrella type human resources agency would be the most effective site in state government for mental retardation programs. Access to programs and continuity between services may increase to a more optimal level since the reorganization of human resources agencies.

The exceptions to the increased accessibility and continuity lie in the programs offered by the Department of Education. Their Bureau of Rehabilitation Services (BRS) and the Division of Special Education seem to open a gap with the Division of Developmental Services (Department for Human Resources, Bureau for Health Services). If the Bureau of Rehabilitation Services and Division of Special Education were placed in the Department for Human Resources, then a gap might be created between B. R. S., Special Education and the remainder of the Department of Education.

## V. RECOMMENDATIONS

Since the renovation of Outwood has been estimated to cost in excess of \$5 million, Outwood should be closed.

A new facility to replace Outwood should be built in Western Kentucky in such a manner that the facility will be readily assimilated in a community.

The Department for Human Resources should explore the possibilities of utilizing the tuberculosis hospital in Ashland as a site for residential programs for the mentally retarded in Eastern Kentucky.

Placement for mentally retarded individuals in personal care homes should cease until such time that personal care homes become appropriate for the mentally retarded. Relatively objective standards for care in all programs for the mentally retarded should be promulgated and enforced; the standards should encompass all localities where mentally retarded individuals have been placed.

Every aspect of a mentally retarded client's progress should be monitored in order to make objective decisions for future placements. During the monitoring phase the evaluative information should be available to facility directors and administrators in addition to individuals responsible for programs outside the residential facilities. Labels must be avoided, especially when dealing with school systems.

A thorough examination of the state's merit system, as it relates to employees in residential facilities, is in order due to the half staff turnover rates and recruiting difficulties. Immediate corrective measures should be taken upon the delineation of problem areas identified in the merit system.

It would appear to be appropriate for mental retardation programs to remain at their present location in the Department for Human Resources until the effects of reorganization have been observed.

## REFERENCES

- American Association on Mental Deficiency, Manual on Terminology and Classification in Mental Retardation. Baltimore: Garamond/Pridemark Press, 1973.
- Anastasi, A., Psychological Testing. New York: Macmillan, 1968.
- Beaumeister, A., Mental Retardation: Appraisal, Education and Rehabilitation. Chicago: Aldine Publishing Co., 1967.
- Burhnam vs. Department of Public Health of Georgia, 349 F. Supp. 1335 (D.M.D. of Ga. 1972).
- Council for Retarded Children of Jefferson County, Inc. Reported on personal care homes housing the mentally retarded in Jefferson County, Kentucky, 1972.
- Governor's Advisory Council on Mental Retardation. Survey Report on personal care facilities, 1972.
- Health and Social Service Facilities Review Commission, Kentucky General Assembly Report to the Legislative Research Commission, 1973.
- Kentucky Department of Education, Division of Special Education. Status Report: Kentucky's Public Schools, 1973.
- Kentucky Legislative Research Commission. Welfare: Mental Hospitals in Ky. L.R.C. Research Publication No. 24, 1951.
- Kentucky Mental Retardation Planning Commission. Pattern for mental retardation programs and services, 1965.
- Mills vs. Board of Education of District of Columbia, 348 F. Supp. 866 (1972).
- Nirji, B. "The normalization principal - Implications and comments." Journal of Mental Subnormality, 16 (31,2) 62-70, 1970.
- Pennsylvania Association for Retarded Children vs. Pennsylvania, 334 F. Supp. 1257 (E.D. Pa. 1971).
- President's Committee on Mental Retardation. Federal programs for the retarded. Washington, D.C.: U. S. Government Printing Office, 1972.

- Reuthebuck, G. "State aid to parents of retarded children." Ky. Legislative Research Commission, Staff Memorandum No. 374, 1973.
- Roos, P. "Basic facts about mental retardation," in Ennis, B. and Friedman, P., (Eds.), Legal Rights of the Mentally Handicapped. Vol. I, New York: Practising Law Institute, 1973.
- Spielberg, A. "Teacher reports of expectations for the mentally retarded" presented to the Am. Assn. on Mental Deficiency, 1973.
- Tarjan, G., Wright, S., Eyman, R., and Keeran, C. "Natural history of mental retardation: Some aspects of epidemiology," American Journal of Mental Deficiency, 77(4), 369-379, 1973.
- World Health Organization, Joint Expert Committee on the Mentally Subnormal Child. The Mentally Subnormal Child, Technical Report Series No. 75, 1954.
- Wyatt vs. Stickney, 325 F. Supp. 781 (D. Ala. 1971).



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